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**Title: ‘...But I’m still tired’: The experience of fatigue among South African adolescents receiving antiretroviral therapy**

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# **Title: ‘...But I’m still tired’: The experience of fatigue among South African adolescents receiving antiretroviral therapy**

## **Abstract**

In adults with HIV, fatigue is a common and disabling symptom associated with suboptimal adherence to antiretroviral therapy (ART), poor health and well-being, reduced economic productivity, and increased health care resource use. Fatigue among adolescents with HIV is relatively unexplored. We recruited 14 adolescents with HIV receiving ART in South Africa whom we interviewed about fatigue. We used thematic analysis to analyse the data.

Participants reported difficulties in maintaining concentration at school and resorting to self-care strategies such as napping during school hours. Adolescents also described actively avoiding activities thought to lead to fatigue and spoke of being socially excluded by their peers. The findings demonstrate that adolescents experienced symptoms consistent with a definition of fatigue, which had implications for their academic and social lives.

**Keywords:** HIV, antiretroviral therapy, adolescents, fatigue, qualitative

## **Introduction**

Fatigue refers to decreased capacity for activity due to an imbalance in the availability of resources needed to perform that activity. “Chronic fatigue”, which is ongoing physical and/or mental exhaustion and tiredness that persists for at least one month (Voss, Portillo, Holzemer, & Dodd, 2007) is commonly reported among specific chronic illness populations, including rheumatoid arthritis (Varni, Burwinkle, & Szer, 2004), chronic pain (Gold, Mahrer, Yee, & Palermo, 2009), neurological conditions (Nutini, Karczewski, & Capoor, 2009) and multiple sclerosis (Banwell et al., 2007).

Among adults with HIV, fatigue is a common and disabling symptom that is associated with poorer treatment adherence (Gay et al., 2011), greater functional impairment, and lower survival rates (Justice et al., 1999), and with poorer health, lower work productivity, and increased health care resource use (DiBonaventura, Gupta, Cho, & Mrus, 2012).

To our knowledge, no research has been conducted on fatigue in adolescents living with HIV. We explored the lived experience of fatigue among a sample of South African adolescents receiving antiretroviral treatment (ART).

## **Method**

### ***Setting and participants***

Participants were HIV-infected adolescents aged 11-18, attending ART clinics in South

Africa. Participants had to be competent in either English or Afrikaans, and not require urgent medical attention; or have severe mental health problems (e.g. psychosis).

### ***Procedure***

We received approval from the Stellenbosch University Health Research Ethics Committee, and permission from relevant health authority and clinic managers.

Interviews were audio recorded, transcribed and anonymised, and translated into English where necessary. Thematic analysis was used to analyse the data (Braun & Clarke, 2006). Themes emerged from the data, with no themes specified a priori.

### ***Measures***

Interviews were guided by an interview schedule (appendix 1) exploring how fatigue impacted participants' day-to-day activities, and how they managed and coped with fatigue. The Chalder Fatigue Scale (CFS) (Chalder et al., 1993) measured fatigue severity, and the Revised Children's Anxiety and Depression Scale (RCADS) depression and generalised anxiety subscales measured mood and anxiety (Chorpita, Yim, Moffitt, Umemoto, & Francis, 2000).

### **Results**

Fourteen participants were interviewed (table 1). Using a cut-off score of  $\geq 4$  (Cella & Chalder, 2010), bimodal scoring on the CFS identified 12 of the 14 adolescents as fatigued.

Participants reported sleep disturbance, unrefreshing sleep, pain, poor concentration and/or memory, and a lack of energy which were not ameliorated by sleep. We identified three overarching themes namely, the impact of fatigue on daily functioning, strategies to

overcome excessive tiredness, and adolescents' understanding and experience of their illness.

### *Impact on Functioning*

Participants avoided vigorous physical activities such as sports as a result of their fatigue. For example, Cassandra stated “*I don't feel like doing the sport anymore because it just makes me more tired than I already am*”.

Fatigue impacted on functioning and productivity in school and participants reported sleeping at their desks. Lisa stated “*... sometimes when my teacher is teaching I am very tired and I sleep in the class so my teacher will shout at me....*”

Due to poor concentration and memory and a general lack of energy, adolescents struggled with the demands of school.

*When I'm doing my homework then I will become tired and just close the books and think that I will finish them in the evening or the next morning. (Brenda).*

Fatigue influenced participants' social interactions. Lisa said “*When I play with my friends I feel tired and I just want to sleep, sometimes*”. Participants felt that their peers did not understand their tiredness. For example, Cassandra reported that “*They can't understand why I'm tired every time.*”

Adolescents stated that their fatigue resulted in social exclusion, which for some generated difficult feelings including anger. For example, Cassandra, who wanted to sleep rather than to socialise stated:

*When I'm tired ... I just want to be alone and sleep. Sometimes my friends come to my house and then I can't sleep and then they want to play there and then I get very angry.*

Participants spoke about sadness and mood fluctuations, for example *"I feel so happy sometimes, sometimes sad"* (Derek). Mood was not consistently seen as directly linked to tiredness, and participants could separate tiredness from low mood:

*...my mood is not like my tiredness.... My mood only comes now and then. But my tiredness stays.* (Brenda)

Participants lacked motivation as a result of their tiredness. Lisa stated *"I feel tired, I don't want to do some things, I just want to rest"*.

*What helps?*

Helpful strategies included the support of friends and family, rest, and activities which adolescents purposefully engaged in to stay awake.

Short naps in the afternoons, and sometimes during school hours were helpful. Christine said *"I stay in class during break and sleep. When the bell rings I wake up again."*

Activities like cooking, eating, walking, exercising, playing and reading provided stimulation to remain alert.

*Me and my sister would always go for a walk but not too far from our home, just walk around a bit.” (Cassandra)*

Motivation to persist through tiredness was enhanced by support from friends, teachers and family members. Friends relieved some of the fatigue through engagement in conversation and encouragement to play. Brenda stated, *“They are like normal friends. When I tell them that I am tired they will tell me that I can go and lay down or they will do something to wake me up or so”*.

#### *Illness perceptions*

Some participants attributed their fatigue to exertion and activity: for example, *“Because on the Monday we always do a lot of work at school so then I feel tired on a Tuesday”* (Faith).

Other participants attributed their fatigue to hunger, or to medication: *“I think it’s the pills because after I drink the pills it keeps me awake and then I feel tired during the day”* (Cassandra), but not all agreed:

*I don’t think it’s my medication, because I take my medication at night and it’s usually during the day that I feel so tired. (Justin)*

Participants had difficulty making sense of their tiredness, which for some was distressing, for example:

*When it started, I was at the school and I sleep in school, ...and my teacher shouted at me and I cried because I didn’t know what was wrong me. (Lisa)*



## **Discussion**

Adolescents with HIV experienced symptoms consistent with a definition of abnormal fatigue (Aaronson et al., 1999), which impacted on their quality of life, most notably on their school performance and their social lives.

Given that adolescents with HIV are cognitively worse off than those without HIV (Laughton, Cornell, Boivin, & Van Rie, 2013; Sherr, Croome, Castaneda, Bradshaw, & Romero, 2014) it is essential that these additional apparently debilitating symptoms of fatigue are identified early on and remediated for where possible.

Our participants withdrew from social life and abandoned sports, a social activity crucial for forming and maintaining relationships with peers. Prolonged avoidance of activity may escalate depressed mood and perpetuate feelings of anxiety when confronted with activity again. Fatigue is also associated with a loss of motivation to take part in activities, a common consequence of tiredness experienced by adults with HIV (Jenkin, Koch, & Kralik, 2006), and paediatric populations with fatigue (Parslow et al., 2017).

Adolescents spoke of deliberate exclusion from social activities by their peers and perceived this an inability of their peers to understand their experiences of fatigue. Repeated instances of social exclusion led to anger and perpetuated a cycle of negative feelings and thoughts which are consistent with other studies (Power, Badley, French, Wall, & Hawker, 2008; Stormorken, Jason, & Kirkevold, 2015).

Similar to other populations, adolescents had strategies that helped manage their tiredness, such as rest and moderate activity (Jenkin et al., 2006) and social support (Mburu et al., 2014).

Expressing experiences of fatigue, which is a complex and inherently subjective concept,

requires clear articulation of the problem (Jenkin et al., 2006), and may be difficult for adolescents. Although our participants did not attribute their fatigue to a single cause, they were able to distinguish it from tiredness or sleepiness following taking their medication.

### ***Strengths and limitations***

Our data provide insights into the complexity of fatigue experiences in this population and the language used to articulate these experiences. However, we only included adolescents who were able to speak English and Afrikaans. The study design does not enable us to disentangle the complex relationships between fatigue and mood, although participants did seem to view these as separable, and those with high levels of fatigue did not necessarily also score more highly on depression or anxiety.

### ***Conclusions***

Fatigue is a widespread and disabling problem among adults with HIV, and may be also be salient among adolescent ART users. Further research may include investigations of the prevalence and correlates of fatigue among adolescents living with HIV (including mood and anxiety), the efficacy of psychosocial interventions aimed at ameliorating fatigue, and the role of fatigue in ART adherence. Comparing the experience of fatigue in adolescents with HIV to other chronic disease populations, to mental health patients, and to healthy individuals would further the understanding of the similarities and differences between groups.

Table 1. Sample characteristics of adolescents

| <b>Pseudo<br/>nym</b> | <b>Age</b> | <b>Gender</b> | <b>Ethnicity</b> | <b>Chalder<br/>Fatigue<br/>Scale Score<br/>(bimodal)</b> | <b>RCADS<br/>Depression<br/>Subscale<br/>Score</b> | <b>RCADS<br/>Generalised<br/>Anxiety Subscale<br/>Score</b> |
|-----------------------|------------|---------------|------------------|--|--|---|
| Lisa                  | 14         | Female        | African          | 9  | 17   | 15  |
| James                 | 12         | Male          | Coloured         | 3  | 2  | 5   |
| John                  | 13         | Male          | Coloured         | 1  | 5  | 4   |
| Jenny                 | 18         | Female        | Black            | 4  | 3  | 15  |
| Victor                | 16         | Male          | Black            | 6  | 9  | 6   |
| Derek                 | 13         | Male          | Black            | 6  | 7  | 10  |
| Justin                | 17         | Male          | Coloured         | 5  | 7  | 1   |
| Brenda                | 15         | Female        | Black            | 5  | 12   | 5   |
| Christi<br>ne         | 12         | Female        | Black            | 7  | 2  | 6   |
| Violet                | 14         | Female        | Black            | 4  | 4  | 1   |
| Steven                | 16         | Male          | Black            | 11   | 12   | 5   |
| Lucy                  | 13         | Female        | Coloured         | 7  | 0  | 5   |
| Cassan<br>dra         | 17         | Female        | Black            | 8  | 16   | 12  |
| Faith                 | 18         | Female        | Black            | 9  | 7  | 11  |

## Appendix 1: Semi-structured interview topic guide

### **The Lived Experience of Fatigue in Adolescents receiving medication: A qualitative study.**

#### **TOPIC GUIDE**

To explore the lived experience of fatigue in adolescents receiving medication and coping styles, daily routines and sleep, and their perception of the causes

*These questions will be used as prompts to ensure all important areas are covered.*

Welcome, introduction, confidentiality. Discuss consent, sign form or check continues to be happy with consent.

**1. Tell me how fatigue/tiredness/exhaustion affects your life.**

Prompts: how does fatigue/tiredness/exhaustion interfere with your daily life? School?  
Work? Social life? Family?

**2. How do you do things differently day-to-day because of the fatigue?**

Prompts: Are there things that you can't do because you are fatigued? What are they?  
Things you would do if you didn't feel so fatigued/tired?

**3. What do you think is making you fatigued/tired?**

**4. How does fatigue/tiredness/exhaustion make you feel?**

Prompts: Sad? Frustrated? Worried? If so, why?

**5. What do you do to help yourself to feel better when you are feeling fatigued/tired/exhausted?**

Prompts: What makes it worse? What makes it better?

**6. Tell me about your sleep. Do you have problems with sleeping?**

Prompts: How is getting to sleep? And can you stay asleep or do you wake up often?

How is waking up? Do you feel rested when you wake up?

**7. Tell me about your mood.**

Prompts: how does your mood affect your daily life? School? Work? Social life?

Family? How do you do things differently day-to-day because of your mood?

**8. Do you think that fatigue/tiredness/exhaustion, sleep and mood are connected for you? If so, how?**

Prompts: what comes first for you? Fatigue/bad sleep/bad or low mood?

**9. Do you have anything else you would like to add? Do you have any questions?**

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